

ASD & ageing

Here you can find information I have gathered regarding ASD & age for as short and specific a version as possible. As a part of old age it seems logical that there are changes in one's abilities and functions. Older people with autism will naturally have some other needs in relation to older people without autism. The greater or lesser extent.

Ex. The importance of the additional disorders, that maybe means you have been medicated for many years, and the consequences of such long-term medication. For my example it could be the medication of ADHD, sleeping problems and depression. A portion of the medication has been- and is very strong.

Department of Child and Adolescent Psychiatry, Bispebjerg University Hospital, Copenhagen, Denmark has made a study: Mortality and causes of death in autism spectrum disorders, where it is seen that the risk mortality among people with autism was nearly twice as high as the general population. Mortality was particularly high for women. Excess mortality risk has remained unchanged since their first study in 1993 (1993-2008). Scientists believe that in the future, we should focus on better management of the complex relationships between autism and physical illness.

Some people with autism have difficulties to "feel themselves", which can cause significant challenges to the Healthcare system. For example, avoiding going to the doctor. I myself am one of them. I can't endure the hugely stressful experience that I can't communicate or be understood. Most often I get misunderstand and I'm stuck in interpretations of "*normalities*". They do not see me in a whole and instead of getting the help I need, I go home unhappy. So my strategy is that it is better to stay away, so I have one less challenge. Why go to the doctor when it does not make sense?

As in among people without autism, autistic people are also different, where the individual's life history and biology, largely applies. For example there is a difference between aging and, being literally "old". When my husband's grandmother at 87 years was dying, she said that she was ready to die, for she had lived her life and felt enriched, but now she was tired. I understood what she said. It sounded logical.

At the age of 42 years, I already feel tired and often life fatigue. Is that not too early? Psychic there is also days where my mind is crying out for peace. At the same time, I'm not ready to die, for I have my kids where I need to experience more of their future with them. But I am in many ways impoverished and it is as if part of me is much older than my age. I know other people with autism feel the same "fatigue" and the same contradictory dilemma. Others don't feel it. I am sure that it depends on one's individual life story, where my life story opens in this corollary, an impoverished life fatigue.

In a Norwegian study from 2006 on the quality of life and living conditions of the elderly with autism, it was found that quality of life was not particularly good for older people with autism.

Elderly people with autism had:

- Low level of participation in leisure activities - only with paid staff.
- Greater support needs because of greater communication problems in old age.
- More deviant behavior that gives conflicts (counterparty create problems and autism is behavior quotation of Autismwhisper) and the use of force - poorer welfare and adaptation.
- Lower degree of autonomy, greater social isolation - less degree of social inclusion.
- Larger use of sedatives.

Some of the challenges that prove more difficult in elderly people with autism are, due to autism challenges:

- Menstruation Cessation or irregularities
- Mood swings
- Hot Flashes
- Excessively fatigue and increased need for rest
- Difficulty in concentrating
- Lose overview faster
- More forgetful - also by special interest
- Poorer short-term memory
- Incontinence
- Blackouts – stalls
- Lose orientation ability
- Less physical and mental energy
- Feel old - the feeling of even more restrictions
- Stiffness of limb - the body is different
- Less physical mobile - Now also physically limited

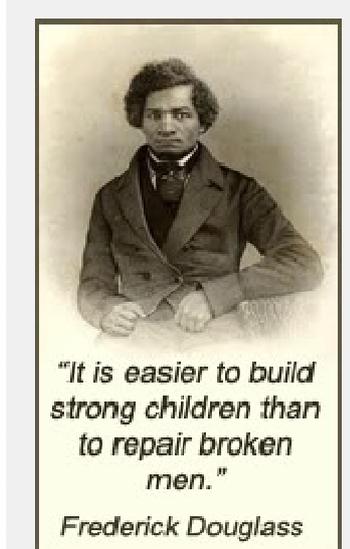
It scares me that I can recognize every single point already at the age of 42 years.

Functions and options have been lost over the last 10 years and I have far more support needs, where I have to fight for my feature, hoping to preserve as many functions I have left as possible, for as long as possible. It gives me the fear of aging. For what does it mean? How long will I preserve my sanity?

It is an ugly and frightening unpredictability when all hope quickly is lost from sight and while I've also lost most of my faith in the world to the impact of negative experiences.

Often my care support time goes to conversations. Required conversations, in order to prevent an even greater sadness and discouragement.

However, I have hope for my children. Hopes that their future looks better - even in old age. Because they have grown up with understanding of their autism, which means that they probably are better equipped.



Here is some information pages - help for the elderly with autism:

- www.autism.org.uk/maturity National Autistic Society England. Stand behind *The Autism Maturity Project*.
They have very good practical guidance. ex.:



The handbook; Aging with autism. 18 pounds as book / free as eBook.



Book; Supporting adults with autism



Book; Support for the bereaved and the dying
Passport to individual autism support



Managing money



Autism alert card

- <http://www.narcis.nl/research/RecordID/OND1341469>

Research in the Netherlands by Dr. Hilde Guerts om; Aging in Autism: A double jeopardy or not?

- http://aaid.org/docs/default-source/annual-meeting/aaid_gerontology_division_symposium_aging_with_autism_submittedtoaaid.pdf?sfvrsn=2

Elizabeth A. Perkins & Karen A. Berkman (2012) artikel; Into the Unknown: Aging with Autism Spectrum Disorders.

- http://www.awares.org/pkgs_files/librarydoc_1058.pdf

Professor Ian Stuart Hamilton, University of Glamorgan's guide:



Autistic Spectrum Disorders: A Guide for People Working With Older Adults.

- <http://www.sesame-autisme-ra.com/>

If you can understand French, here is a website where they have created a housing for elderly people with autism. Here you can see a report with pictures from the project;

<http://www.youtube.com/watch?v=MA95okY17D4>

- <http://www.autismeurope.org/files/files/ageing-report-en-sml.pdf>

Autism Europe: Pjecen; Towards a better quality of life: The rights of ageing people with autism

- <http://www.realdania.dk/filantropiske-programmer/samlet-projektliste/botilbud-aeldre-autisme>

Sofie Foundation and the Autism Society in Denmark have with Realdania developed a model program for housing older people with autism. Model program describes what is important to take into account when building new or rebuilt. Model program can be downloaded for free;

<http://www.realdania.dk/filantropiske-programmer/samlet-projektliste/botilbud-aeldre-autisme/nyheder/%C3%A6ldreboliger-som-botilbud-for-%C3%A6ldre-med-autisme>

Senior housing as housing for older people with autism, with support from Realdania is located Hinnerup Aarhus.

- <http://www.hoejtoft.dk/>

Denmark; Residence for voksne- and older with autism. Located in Bagsvaerd - Denmark.